

# Applied Research intended to improve ASD Identification: A comprehensive review of projects funded in the US from 2008 to 2015

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## Background & Objectives

Concerns about ASD's prevalence and delays in diagnosis mobilized \$3 billion in research funding in the US between 2008 and 2016. Yet recent reports indicate persistent and significant gaps in the timely and accurate identification of ASD. Earlier, we reviewed all projects funded by the National Institutes for Health from 2008 to 2013 focused on ASD identification<sup>1</sup>. Only 9 projects (1% of all ASD research funding) focused on improving ASD identification among community providers.

How can research ensure broad improvements in identification? Have funders focused on developing clinical tools? To what extent have they prioritized the kinds of studies needed to translate research into community practice? Have the resulting projects achieved their goals, by at least resulting in publications that report the results (knowledge impact), if not clear recommendations for practice (practice impact), demonstrated effectiveness in programs outside of research settings (program impact), and at scalable levels across a region (population impact)?

Our objective was to review all US funding from 2008 to 2015 for clinical and implementation research to improve ASD identification, whether this resulted in relevant publications, and whether this relationship depended on the background of Principal Investigators (PIs). We use a new research roadmap for improved identification that includes Clinical & Implementation Research as the first two stages of Applied Research (see Figure 1).

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Insert Figure 1 about here  
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## Methods

### Steps

1. We downloaded information on all grants in the Autism Research Database from 2008 to 2015 listed under (Q)uestion 1: Screening/Diagnosis (Figure 2).
2. We excluded projects listed under sub questions clearly associated with basic research (Q1.LA, Q1.LB, Q1.LC, and Q1.SE).
3. We reviewed each project abstract to extract specific aims related to phases of clinical research (C-Aims) and implementation research (I-Aims).
4. We assembled the PI's original, peer-reviewed articles, published since the project's inception, and that seemed likely to report project results.

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<sup>1</sup> This handout integrates two separate but related presentations at IMFAR 2019: "Research intended to improve ASD Identification: A comprehensive review of projects funded in the US from 2008 to 2015" and "A national survey of clinical research seeking to develop better tools for ASD identification: Priorities and outcomes"

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5. We extracted goals from these publications that addressed applied research (P-Aims)
6. We sought to align P-Aims from the PI's publications with the C-Aims and I-Aims from the PI's project.
7. We searched for bios or resumes indicating the PIs' clinical training and post-graduate clinical experience outside of research settings.

Other details regarding methods are available on our website. As analyses are ongoing, updates will be posted at regular intervals at <http://www.asdroadmap.org/research-roadmap-for-asd-screening.html>.

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Insert Figure 2 about here  
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## Results

### Knowledge Impact

Clinical Research: For 24 projects, the primary aim was to improve ASD identification (Figure 3). These 24 projects accounted for 8% of all funding targeting identification (Figure 5), or about 1% of all research funding. The primary aim was clearly addressed in a related publication in fewer than 50% (10/24) of projects. Eleven of the remaining 14 projects were completed at least 3 years ago. Overall, we found about 40% (23/55) of research aims that were addressed in a subsequent publication, on average 2 years after the completion of the project. For 11 of 28 projects, we could find no publications in which specific results related to project objectives were reported.

Implementation Research: For 14 projects, the primary aim was to improve ASD identification (Figure 4), These accounted for 6% of all funding targeting identification (Figure 5), or about 1% of all research funding. The primary aim was clearly addressed in a related publication in fewer than 40% (5/14) projects. Three of the remaining 9 projects were completed at least 3 years ago. Overall, we found about 50% (15/29) of research aims that were addressed in a subsequent publication, on average 1.5 years after the completion of the project. For 6 of 18 projects, we could find no publications in which specific results related to project objectives were reported.

### Focus of research, and changes over time

Some types of research predicted by the roadmap were not found; only one study focused on extending a clinical tool to other populations, and no studies assessed training and related supports for implementation, or sought to demonstrate systematic regional delivery. Otherwise, funding trends were consistent with the roadmap. Clinical research funding focused on validating and adapting practices, and remained stable over time (Figure 5). Implementation research funding increased significantly over time, primarily due to a specific, multi-project initiative funded in 2014.

### Background of PIs

Enough information was obtained to determine the clinical training of 30 out of 35 PIs who received funding to undertake Applied Research. Twenty were clinically trained (most as psychologists or physicians). Of the nine PIs for whom detailed work histories were available, only one had any full-time, post-licensure clinical work experience outside of a research setting.

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None had any experience leading community-based programs focused on delivering clinical or educational services.

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Insert Figures 3, 4, and 5 about here  
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### Conclusions

Little research conducted between 2008 and 2015 to address ASD identification actually focused on directly improving practice. While this increased in recent years, even then it constituted a negligible (3%) proportion of overall research funding. The actual knowledge impact is more limited because of apparent gaps in publications addressing the primary hypotheses of funded projects. For example, we could only find publications clearly addressing primary objectives for only half of the projects. These gaps appear to extend to secondary hypotheses. Even when findings are published, this only occurs 18 to 24 months after the project's completion. These gaps and lags in funding and publications mean that the research likely to directly and immediately improve ASD identification in the community actually represents a drop in the bucket of overall funding and effort (Figure 6).

Gaps in the training and experience of PIs are unsurprising, but underscore that some seek funding to solve problems for which they lack training, or have limited, direct practical experience. The gaps in funding and in the background of PIs are similar to those observed for analyses of NIH funding between 2008 and 2013<sup>1,2</sup>. We therefore expect to find similar patterns for research funded between 2008 and 2015 to improve intervention.

These data are preliminary. We did not consider the background of co-investigators, or data on projects funded after 2015. Many PIs did not respond to requests to add other relevant publications. We lacked information on the work history of more than ½ of the PIs who were clinically trained. It is also conceivable that a small number of other projects were coded under other Q1 categories or other questions.

Future analyses may reveal other gaps – e.g., how many projects yielded specific recommendations that practitioners or program leaders found useful? To what extent have researchers demonstrated an impact on practices used by the programs in their own community? Have these resulted in any meaningful impact on the population as a whole? These factors taken together - the lack of applied research into identification practices, combined with publication lags and gaps, and the limited impacts which result - readily explain persistent and significant gaps in timely and accurate ASD identification across the US.

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Insert Figure 6 about here  
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### References

1. Doehring, P. (2018a, May). Priorities established by the Combating Autism Act for improving ASD identification: Looking beyond ideas and instruments towards implementation. Paper presented at the International Society for Autism Research, Rotterdam, NL.
2. Doehring, P. (2018b, May). Priorities for treatment and services established by the Combating Autism Act: Costs and outcomes. Paper presented at the International Society for Autism Research, Rotterdam, NL.

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Figure 1: A Research Roadmap for ASD Identification

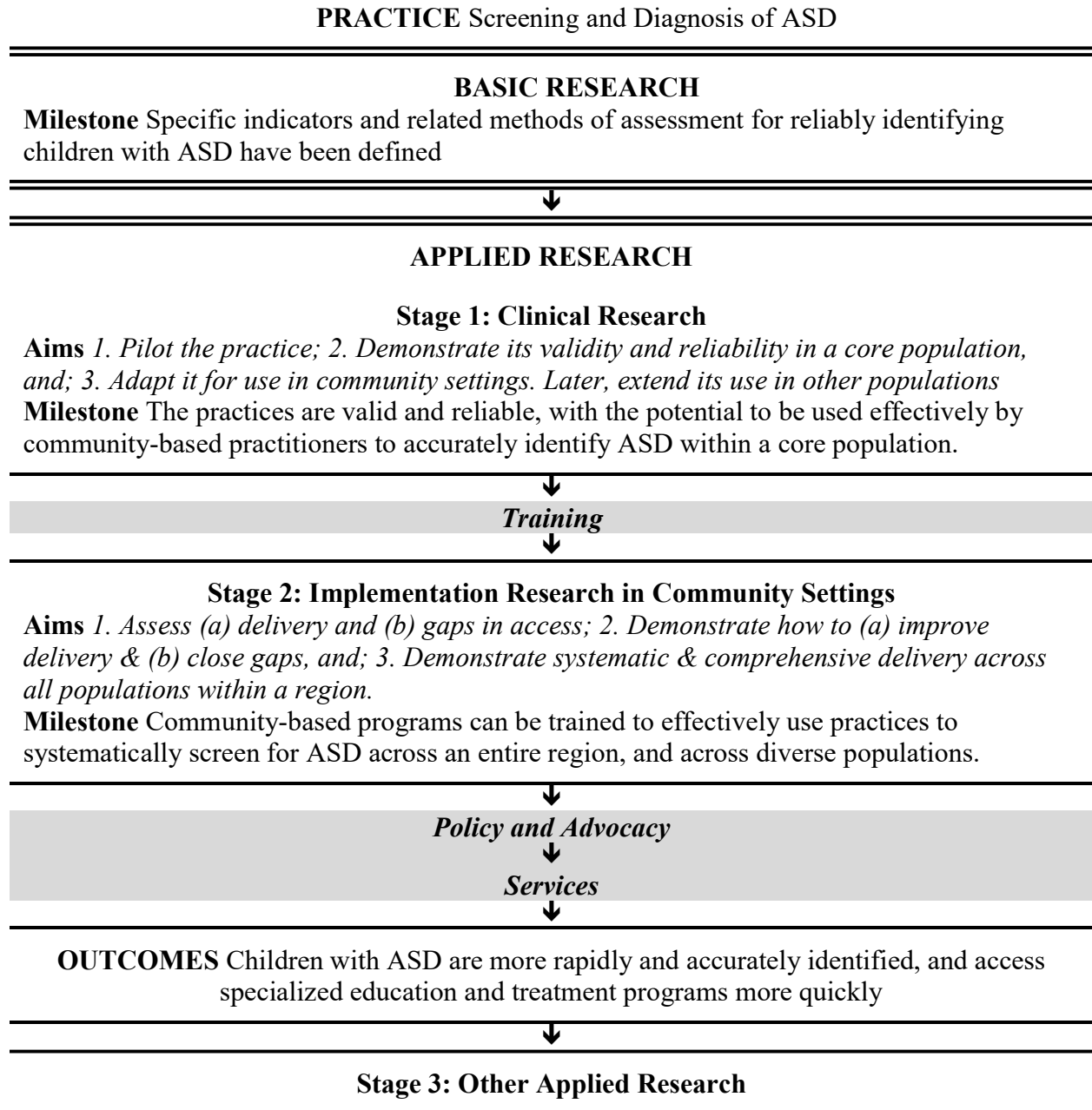


Figure 2: Steps 1 and 2: Extracting grants likely to involve Applied Research focused on ASD identification

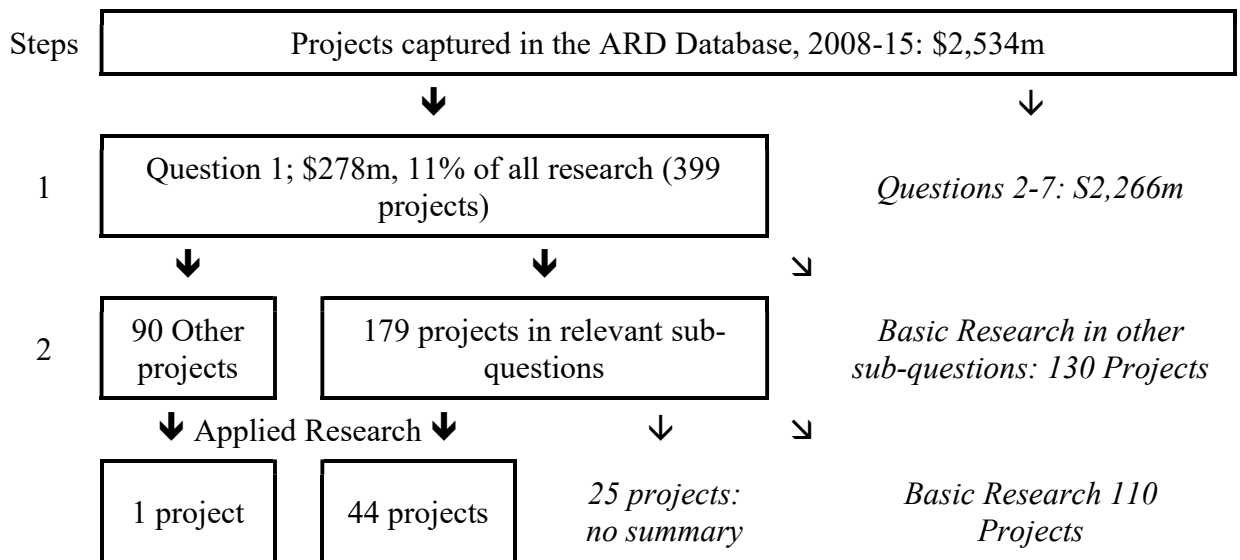
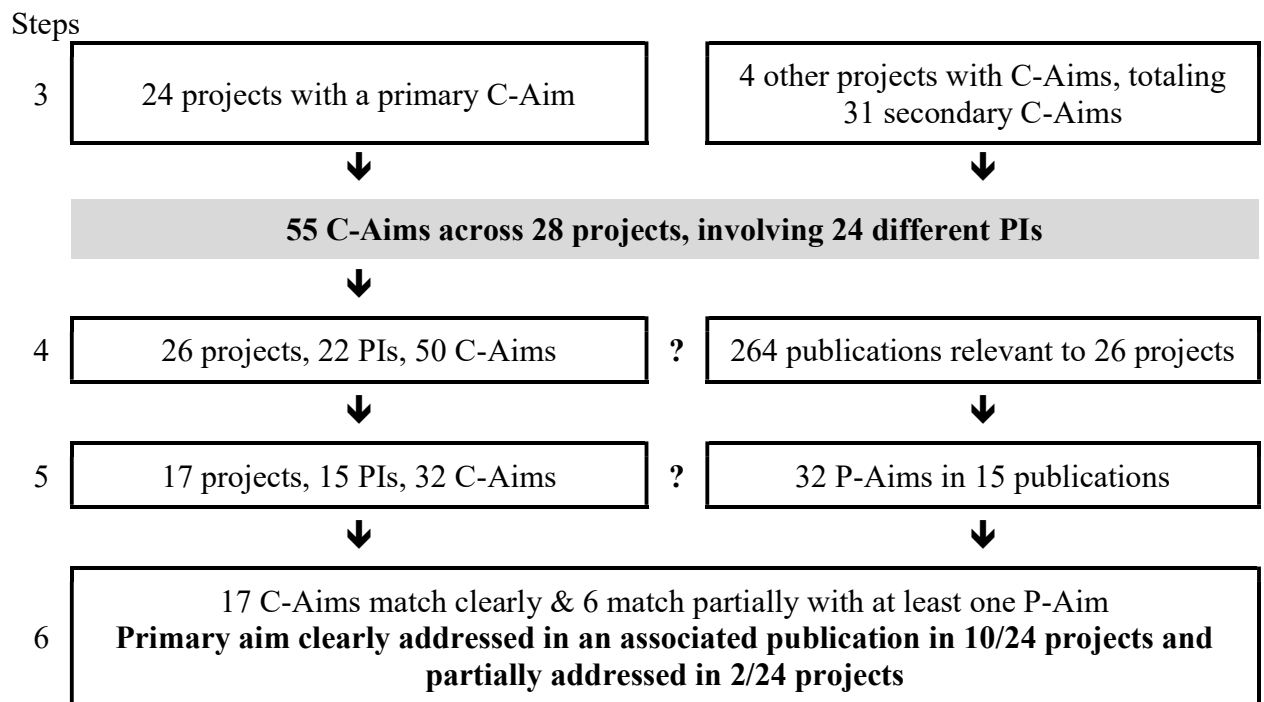
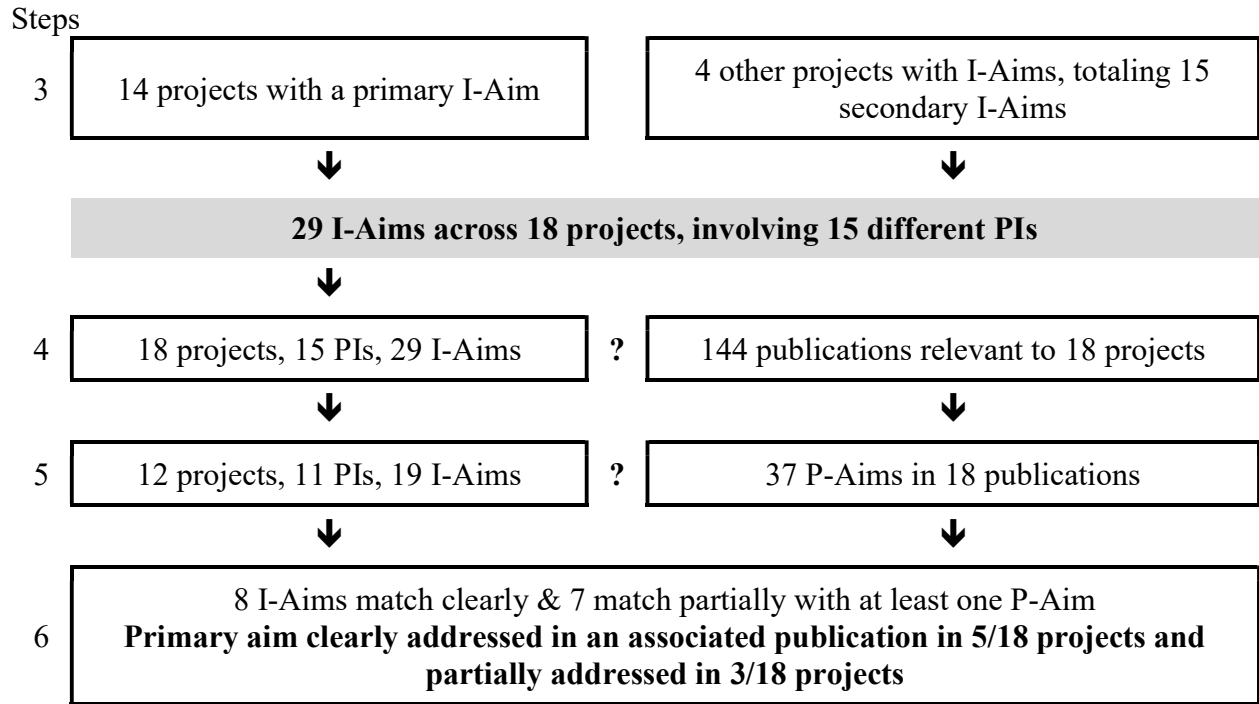


Figure 3: Matching Clinical Research Aims (C-Aims) and Publication Aims (P-Aims)



**Figure 4: Matching Implementation Research Aims (I-Aims) and Publication Aims (P-Aims)**



**Figure 5: Total research (millions) and % of all Q1 funding for projects with primary clinical and implementation research aims**

Period	2008-10	2011-13	2014-15	Total
<b>Clinical Research Aims</b>				
1. Pilot	\$<1m (<1%)	\$2m (2%)	\$1m (2%)	\$3m (1%)
2. Validate	\$3m (3%)	\$3m (3%)	\$3m (4%)	\$9m (3%)
3. Adapt	\$3m (3%)	\$4m (4%)	\$3m (6%)	\$10m (4%)
Total	\$6m (5%)	\$9m (10%)	\$7m (11%)	\$22m (8%)
<b>Implementation Research Aims</b>				
1b. Assess gaps	0	\$<1m (<1%)	\$2m (1%)	\$2m (1%)
2a. Improve delivery	0	\$<1m (<1%)	\$4m (7%)	\$4m (1%)
2b. Close gaps	0	\$1m (<1%)	\$9m (14%)	\$10m (3%)
Total	0	\$1m (1%)	\$15m (23%)	\$16m (6%)
All Applied Research	\$6m	\$10m	\$21m	\$38m
% All Q1 Research	5%	11%	34%	14%
% All Research	1%	1%	3%	2%

**Figure 6: The impact of Applied Research: A drop in the bucket?**

**All Research from 2008-2015: \$2.5 billion**

**Projects focused on improving identification: 11%**

*14% (\$38m) of all research under Question 1 was **Applied Research: <2%***

*Fewer than 50% of the projects have resulted in a publication that reported a test of the primary objective; i.e., had an **Impact on Knowledge: <1%***

*Future research will consider how many projects resulted in changes in practices and community programs, and that ultimately helped to demonstrably improve population outcomes; i.e., had an **Impact on Practices? Programs? Populations?***

